



EUROPEAN  
MULTIPLE SCLEROSIS  
PLATFORM

*Defeating MS Together*  
**The European Code of  
Good Practice in MS**

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“ One morning, when I was just 28 years old, I awoke to find myself paralysed down my left side and with no balance or co-ordination, and with double vision. I had no warning of this and felt very afraid. In July 2000, I was diagnosed with relapsing remitting multiple sclerosis.”

[L. McVay, person with MS, UK]

# Foreword

**Imagine how frightening it would be to suddenly experience a paralysis, lose your balance or not be able to see properly and not know what is happening to you. Your symptoms may become more frequent and more severe and significantly affect your quality of life. This is the reality for thousands of people across Europe diagnosed with multiple sclerosis (MS) every year. Over 700,000 people in Europe are living with MS and yet the treatment and support they receive varies widely depending on where they live. Consequently, many people with MS are missing out on the vital care they need. This is unacceptable.**

The European Code of Good Practice in Multiple Sclerosis was originally published in 2005 to highlight the issues faced by people with MS across the European Union (EU) and the measures needed to drive improvements. Since developing the original Code, over nearly ten years the European Multiple Sclerosis Platform (EMSP) has worked closely with its members and the European Institutions to create tools to transform the Code's principles into national policy and, more importantly, standards of practice. A number of key initiatives have been devised to support implementation at national level across the EU, including:

- Multiple Sclerosis Information Dividend (MS-ID)
- MS Barometer
- High-level roundtables on MS
- European MS Register (EUREMS)

EMSP undertook central coordination of activities that, along with EU financial support, helped to ensure a high level of consistency while also making it easier for countries with limited resources to pursue implementation of the Code. A number of MS societies have managed to drive change by using the Code to raise awareness of issues for people with MS and what was needed to improve matters, for example in Slovenia where the National Health Insurance Institute agreed to take measures to make health insurance more accessible for people with MS.

Despite the progress achieved by these initiatives, there is still a long way to go. People with MS across the EU still face wide variation in access to treatment and support as well as barriers to employment and benefits. In addition, we still need to better understand the onset and progress of MS, including in those diagnosed as children,

and how to effectively treat it. The MS community across the EU, including people with MS, their carers, advocacy organisations, healthcare professionals and researchers, alongside policy makers must work together in order to generate meaningful change.

The societal costs of MS rise exponentially as MS progresses. Taking action is not only essential to improve the lives of those affected by MS; timely access to treatment and services provides multiple benefits to MS patients and to society as a whole. When their condition is effectively managed and they have access to the right support, people with MS have a higher level of health and overall wellbeing for a longer period of time. They are able to remain more active in the workforce and in their family lives, and to maintain a higher degree of social and economic independence. Early investment in appropriate

treatment and services can significantly delay the substantial economic and human costs associated with advanced stages of the disease.

In *Defeating MS Together*, the updated and refreshed version of the Code, we present the current issues facing people with MS, and those who care for them, and set out clear calls to action aimed at improving their lives and reducing inequalities.

We call on you all to join us and commit to achieving our Calls to Action so that we ultimately defeat MS. Together we must:

**Commit. Support. Advocate. Act.**



John Golding  
*EMSP President 2010-2014*



Maggie Alexander  
*EMSP Chief Executive*



Together we must:  
Commit. Support.  
Advocate. Act.

PHOTO CARLOS SPOTTORNO





PHOTO: JUANES R. BASSO

## Executive summary

While there is currently no cure for MS, treatments exist that help to slow progression of the disease and manage the condition alongside rehabilitation and other supportive therapies. However, there is huge variation in access to treatments and therapies for people with MS depending on where they live in the EU and beyond. Disparities between countries are striking in areas such as:

- Access to equipment and health professionals to confirm diagnosis
- Availability of medication and reimbursement of costs
- Opportunity to participate in working life.

Paediatric MS still requires much more attention to advance our understanding of the particular needs of children and adolescents with MS. The cohesion of MS research projects needs improving at a strategic level and

collaboration across the EU must be promoted to ensure swifter learning and best practice implementation. In addition, the needs of those who spend their lives caring for people with MS are being overlooked.

Individuals and organisations across the EU need to come together to channel their efforts in tackling this debilitating disease and making life better for the hundreds of thousands of people with MS and their carers.

*Defeating MS Together* has been developed as a vital tool in targeting attention on the issues that matter, highlighting the particular areas in which improvements are urgently needed. It is much more than a set of ideals. It stresses the need for the whole MS community, alongside policy makers, the media, clinicians and academics, to work together to address 12 specific Calls to Action.

*Defeating MS Together* sets out 12 Calls to Action, under a Core Principle and 5 Action Areas. It has been nearly 10 years since the original Code came into effect. *Defeating MS Together* now looks forward another decade by setting out a clear ten-year timeline for these actions to stress the urgency of the calls and help guide progress. These calls are expanded and discussed in detail in the following sections.

### Empowering People with MS

#### CALL 1

By 2015, all those who work with people with MS, and their carers, (whether health or social care professionals, researchers, employers or policy-makers) should positively encourage their meaningful involvement and provide appropriate information and support to enable them to take part in decision-making that ultimately affects their lives.

#### CALL 2

By 2015, all healthcare professionals must recognise the information needs of people with MS, and their carers, and provide honest and useful information about their condition, prognosis and treatment, therapies, rehabilitation and support available to them.

## ACTION AREA 1

### Ensuring Access to MS Treatment, Therapies, Rehabilitation and Services

#### CALL 3

By 2018, all people with MS across the EU must be able to access the recommended treatments, therapies, rehabilitation and skilled, professional support to enable them to be as well as possible for as long as possible and to be able to contribute to society.

#### CALL 4

By 2020, healthcare commissioners and providers across the EU must fully recognise the importance and value of MS nurses and ensure there are adequate numbers employed to provide appropriate support to all people with MS who would benefit.

## ACTION AREA 2

### Better Understanding and Treatment of Paediatric MS

#### CALL 5

By 2018, all children and adolescents with MS across the EU, and their families, must be able to access the recommended treatments, therapies, rehabilitation and skilled, professional support to enable them to cope with their diagnosis, achieve a good quality of life and to take part in society.

#### CALL 6

By 2020, the EU and other research funders must provide increased resources for, and researchers must design, more targeted clinical trials to identify the most effective treatments for children and adolescents with MS.

### Focusing MS Research

#### CALL 7

By 2022, the EU and other research funders must allocate particular attention and resources to research into progressive MS.

#### CALL 8

By 2024, researchers, research funders and MS organisations across Europe must collaboratively develop a series of shared research and data management strategies, underpinned by central EU resources as well as national level funding.

### Enabling Employment, Job Retention and Education

#### CALL 9

By 2018, all employers and education providers must be aware of legislation and policies requiring the need to provide support for people with chronic conditions, such as MS, and take steps to ensure this provision for all those who need it.

#### CALL 10

By 2022, all policy-makers and employers must recognise the need for greater flexibility within social, disability and workplace benefits to account for the fluctuating needs of people with relapsing remitting MS.

## ACTION AREA 5

# Monitoring progress

### Supporting and Empowering MS Carers

#### CALL 11

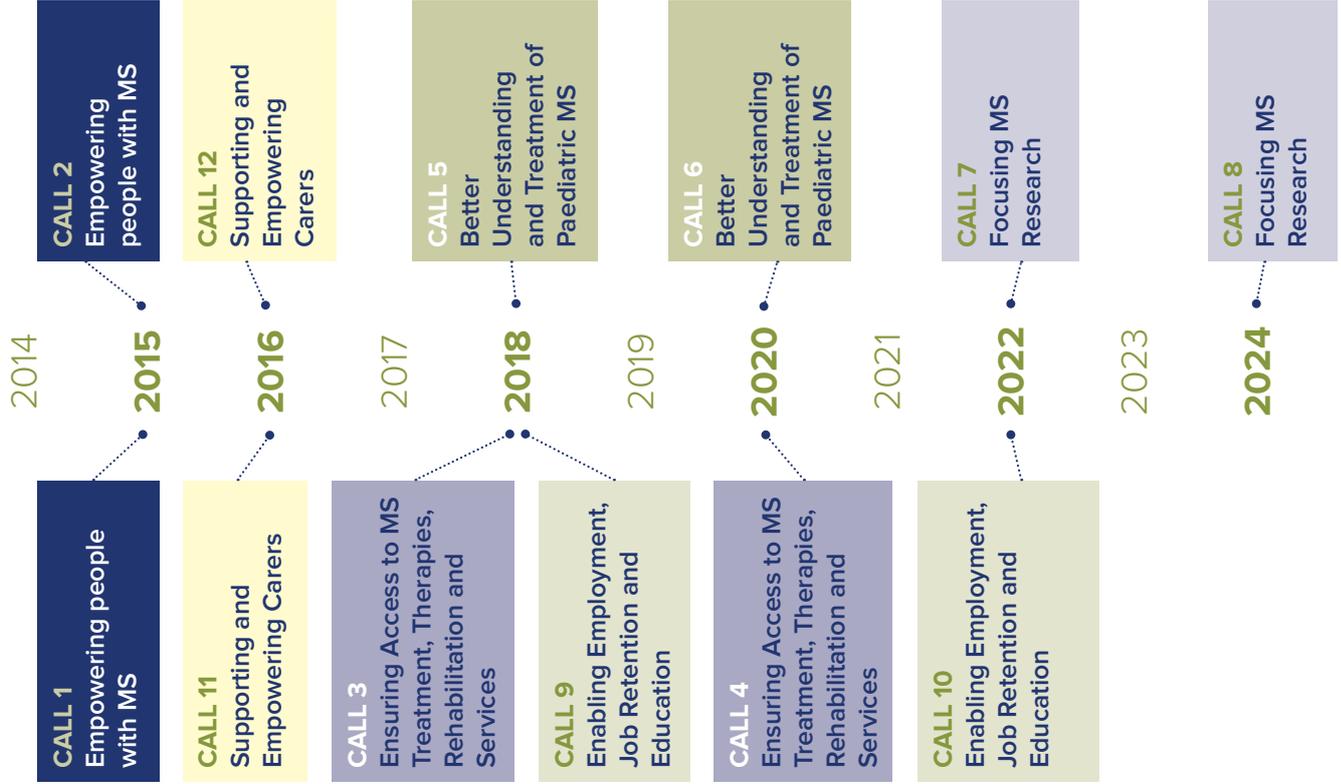
**By 2016, all those who work with people with MS and their carers must take the particular needs of carers into account and offer support where appropriate.**

#### CALL 12

**By 2016, the MS community should develop and promote a resource (such as an online hub) enabling MS carers from across the EU to communicate with each other, share their experiences and develop a voice to be able to express their particular needs and preferences.**

It is essential that momentum in achieving the Calls to Action is instigated and maintained if defeating MS is to become a reality. *Defeating MS Together* must be used as a strategic, active tool to secure progress. Progress against the Calls to Action will be monitored by EMSP. An annual progress check will be coordinated and reported by EMSP and targeted action plans will be developed in response to areas where progress is found to be absent or limited.

# TIMELINE







## What is Multiple Sclerosis (MS)?

**Multiple sclerosis (MS) is the result of damage to myelin – a protective sheath surrounding nerve fibres of the central nervous system.**

**When myelin is damaged, this interferes with messages between the brain and other parts of the body.**

MS is a complex, neurological condition and no two people are affected in the same way. An unpredictable and progressive disease, MS profoundly affects the quality of life of the person from the moment of diagnosis until the end of their life. Symptoms range from fatigue, depression, bladder and bowel problems, and abnormal speech to loss of memory, severe mobility problems and blindness in extreme cases. MS is associated with high costs for MS patients, their families, and society as a whole.

There is currently no cure for MS, nor preventive measures, but the condition can be managed through specialised help, starting with early diagnosis and continuing with person-centered therapies and appropriate medication.

**Over 700,000 people in Europe are living with MS** and an estimated one million people are affected through their role as carers and family members of people with MS.

**Most people are diagnosed between the ages of 20 and 40**, and for half of them unemployment follows, on average, three years after.

**MS is twice as common among women as among men.**

At the point of first diagnosis, there are 3 main types of MS:

- **85% of patients** are diagnosed with **relapsing remitting MS** – where symptoms come and go, often as sudden attacks

- **10% of patients** are diagnosed with **primary progressive MS** – where symptoms gradually get worse over time, rather than appearing as sudden attacks, leading to increasing disability

- **5% of patients** are diagnosed with **progressive relapsing MS** – where the condition gets gradually worse but there are also distinct relapses

**8 out of 10 people** with relapsing remitting MS go on to develop **secondary progressive MS** – where there is a sustained increase in disability, independent of any relapses.

It is estimated that dealing with **MS in Europe currently costs 15 billion euros per year** and the financial impact is expected to increase significantly in the coming years.

## About Defeating MS Together

**There is a huge disparity in the way in which people affected by MS are treated across the EU, causing a detrimental impact on the quality of life of many people with MS and those who care for them. *Defeating MS Together* is a political and practical tool to challenge these inequities and focus efforts on 12 key Calls to Action.**

*Defeating MS Together* is an updated version of The European Code of Good Practice in Multiple Sclerosis (Code) that was originally launched in 2005. Whilst the world has moved forward in some ways since that time, many challenges still remain for people with MS and those who care for them. The new Code sets out the current issues and what needs to be done to make rapid improvements. It is aimed at both the MS community throughout the EU and all those who

can work with them to make a concerted and genuine impact on improving life for people with MS – policy makers and the media, as well as clinicians and academics.

The Code also refers to detailed Consensus Statements that have been developed by leading experts on particular key areas to provide best practice advice for the care and treatment of people with MS. These Consensus Statements should be used alongside the Code to ensure that all people with MS across the EU, irrespective of age and circumstance, benefit from equal access to treatment, support and the outcomes of MS research. The Consensus Statements available are:

- Basic and Escalating Immunomodulatory Treatments in Multiple Sclerosis – Current therapeutic recommendations. *2008*
- Symptomatic Treatment of Multiple Sclerosis. *2008*
- Consensus statement – Evaluation of New and Existing Therapeutics for Paediatric Multiple Sclerosis. *2012*
- Recommendations on Rehabilitation Services for persons with Multiple Sclerosis in Europe. *2012*
- Palliative Care Among People Severely Affected with Multiple Sclerosis. *2014*
- Moving Towards the Pan-European Unification of Multiple Sclerosis Nurses – A consensus paper. *2013*
- Principles to Promote the Quality of Life of People with Multiple Sclerosis (developed by the Multiple Sclerosis International Federation). *2005*

In 2003, the European Parliament approved a report, based upon a petition submitted by a British person with MS, Louise McVay, analysing the varying experiences of people with MS across Europe. The European Parliament adopted an important Resolution urging EU health ministers to develop a European Code of Good Practice in Multiple Sclerosis. EMSP seized on the initiative. With financial support from the EU and assistance from its partners across Europe, EMSP developed the Code, drawing on European consensus and reference documents focusing on MS and the United Nations Convention on the Rights of Disabled People.

The Code was launched in 2005, with the intent of providing a practical framework for optimal approaches to issues of fundamental importance to people with MS and continuing the political momentum created by the European Parliament report and Resolution on MS. It outlined the best practices and approaches in relation to treatment, employment and empowerment of people with MS, as well as the need to optimise research efforts in MS through pan-European coordination. The aim was to achieve the best quality of life possible for people with MS.



PHOTO CARLOS SPOTTORNO



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## Areas for action

There are five priority action areas, tied together under a core principle, that require urgent attention if the lives of people affected by MS across the EU are to be significantly improved. These areas for action are outlined below.

## CORE PRINCIPLE

### Empowering People with MS

Underpinning all the action areas is the core principle and fundamental requirement to support and enable the participation and empowerment of people with MS. It is essential that all people with MS, and their carers, are given the opportunity to be involved in decision making about their treatment and care and to feed into research and policies relevant to the condition. In addition, better partnerships between people with MS, the organisations that represent them, healthcare professionals, researchers, and policy makers are needed to foster effective collaborations and drive improvements to better meet patient needs in real-world scenarios.

Involving and empowering people with MS, and their carers, has many benefits including:

- increased understanding and acceptance of their condition
- better compliance with treatments
- services are designed to better meet

#### CALL 1

**By 2015, all those who work with people with MS, and their carers, (whether health or social care professionals, researchers, employers or policy-makers) should positively encourage their meaningful involvement and provide appropriate information and support to enable them to take part in decision-making that ultimately affects their lives.**

patient needs

- clinical trials are better designed to include patient preferences
- policies are created that better match real-world scenarios and expectations and deliver tangible benefits.

#### CALL 2

**By 2015, all healthcare professionals must recognise the information needs of people with MS, and their carers, and provide honest and useful information about their condition, prognosis and treatment, therapies, rehabilitation and support available to them. They should also have access to user-led, self-management courses to support independent living. It is essential to enable people with MS to be as fully involved in decision-making about their treatment and care as they choose to be.**

## Ensuring Access to MS Treatment, Therapies, Rehabilitation and Services

At present, there is no known cure for MS. However, a number of approved treatments are currently available, which aim to:

- reduce the frequency and severity of relapses
- slow the progression of MS
- and slow the development of disability.

Timely and ongoing access to high quality treatment, therapies, rehabilitation and services is critical for ensuring the quality of life of people with MS. Lack of access severely diminishes the quality of life, and has been shown to lead to missed opportunities to more effectively manage the progression of the disease. However, there is tremendous variation in access to optimal

treatment and care across the EU.

The percentage of people with MS receiving disease-modifying treatment varies greatly across the EU. In 2011, data showed that while in countries such as Austria, Germany, Italy and Portugal the large majority of people with MS received such treatments, fewer than 30% received them in countries such as Bulgaria, the Czech Republic, Poland and the UK. Similarly, fewer than 30% of people with MS in Bosnia-Herzegovina, Russia and Sweden received symptom-relieving treatment, while those in many other countries fared much better. Rehabilitation can help people with MS carry on with their daily lives, for instance after a severe relapse. However, not all countries provide comprehensive rehabilitation services for people with MS. If you live somewhere like Denmark, Iceland or Croatia, you will probably

get access to such services, but if you live in Belgium, Ireland, Russia or Belarus, there is a high chance that you won't.

It is essential that all people with MS, regardless of where they live, get access to early diagnosis, appropriate treatments, therapies, rehabilitation, interdisciplinary resources and specialists, comprehensive information and palliative care. Cross-border healthcare is becoming increasingly important and the EU Directive 2011/24/EU on Patients' Rights in Cross-border Healthcare aims to assist individuals in accessing the care they need within Europe. Healthcare professionals from all EU countries need be familiar with this Directive and to support their MS patients in accessing appropriate care, even if they need to travel to another country to receive it.

In addition, the role of the MS nurse is diverse and varies substantially across the EU, leading to inequalities in patient access to care and advice. The nurse is a key player in the provision of information, support and advice for patients with MS from the time of diagnosis and throughout the disease trajectory, providing a coordinated approach to care. However, according to the MS NEED: European Survey, 31 % of nurses in Europe feel that standards of MS care are not well maintained in their country. This is mainly due to inadequate treatment, information and education. The MS NEED project identified the need for a European consensus on the roles and responsibilities of the MS nurse to promote consistency of care for people with MS across all countries.

“ By defining the new, evolved role of MS nurses and equipping them with the skills and knowledge they need and the recognition they deserve, we hope to see a change in the effectiveness of MS care that extends across the entire multi-disciplinary team which will affect the most important beneficiaries of all – people with MS.”

[EMSP President Anne Winslow]

**CALL 3**

By 2018, all people with MS across the EU must be able to access the recommended treatments, therapies, rehabilitation (as set out in the Consensus Statements listed above, as well as future approved treatments and therapies) and skilled, professional support to enable them to be as well as possible for as long as possible and to be able to contribute to society.

**CALL 4**

By 2020, healthcare commissioners and providers across the EU must fully recognise the importance and value of MS nurses and ensure there are adequate numbers employed to provide appropriate support to all people with MS who would benefit. We also call on the nursing community across Europe to collaborate in defining the key roles and responsibilities of the MS nurse, consolidating existing national tools in the process, to ensure consistency of care for all people with MS. The development of a European MS Nurse Network to share best practice and promote advances in care is also encouraged.

## ACTION AREA 2

### Better Understanding and Treatment of Paediatric MS

Approximately 3–5% of MS patients experience their first MS attack during childhood. The frequency of relapses is higher than in adult onset MS and around one third of children demonstrate evidence of significant cognitive deficits early in the disease course. Although the progression of the disease is typically slower than in adult onset MS, those who develop MS in childhood often reach disability milestones at a younger age.

In paediatric MS most medicines are prescribed off-label since therapies shown to be effective in adult clinical trials and which have been approved for adult MS have not been formally evaluated by clinical trials in children. In some countries, regulatory approval restricts

the administration of MS disease-modifying therapies to patients 12 years and older. As more advanced treatments for MS are approved in adults, healthcare professionals caring for children and adolescents with MS will increasingly face challenges in recommending the most appropriate therapy, given the lack of studies in paediatric MS.

However, as paediatric MS displays a different disease progression from adult onset MS, more research is needed to better understand the prognosis, treatment options and support needs for children and adolescents with MS. There is also the potential for serious long-term side effects of treatment so the most effective treatments tailored to this young MS population are urgently required. Conducting robust clinical trials in paediatric MS patient populations will ensure that all MS patients, irrespective of

age, benefit from advances in MS therapeutics. A diagnosis of MS has a major impact on young patients and their families, therefore psychological and social support is also need to be in place to assist them in facing the physical and psychological limitations in family, school and social activities. A skilled multidisciplinary team

#### **CALL 5**

**By 2018, all children and adolescents with MS across the EU, and their families, must be able to access the recommended treatments, therapies, rehabilitation (as set out in the Consensus Statement listed above, as well as future approved treatments and therapies for this population group) and skilled, professional support to enable them to cope with their diagnosis, achieve a good quality of life and to take part in society.**

is required to effectively care for children and adolescents with MS. It is essential that clinicians have the appropriate expertise so that diagnosis and suitable early intervention and support are not delayed.

#### **CALL 6**

**By 2020, the EU and other research funders must provide increased resources for, and researchers must design, more targeted clinical trials to identify the most effective treatments for children and adolescents with MS. These trials must aim to better understand the particular challenges for, and needs of, this population group and ensure that more evidence-based treatment and support options become available to them.**

## ACTION AREA 3

### Focusing MS Research

MS is a highly complex disease. Currently, experts acknowledge that significant investment will be needed in order to find a cure, or even to identify effective symptomatic treatments or prevention mechanisms. They have identified a number of research priorities, including: the epidemiology, genetics, and clinical pathology of MS, types of therapy, biomarkers and the better understanding of progressive forms of MS. It is a particular concern that at present there is no effective disease-modifying treatment available for progressive MS and no way to accurately and consistently predict progression or prevent it from happening.

The overall impact of research efforts can be undermined by a lack of co-ordination between European countries. To inform and drive better

research and increased understanding of MS across Europe, closer collaboration among EU researchers and other data gatherers is needed. Shared research and data management strategies are required, with more funding provided by both the EU and appropriate agencies at the national level. Initiatives that require particular attention and resources include:

- The development of a national MS register in all European countries and a European MS Register need more support. The European Register for Multiple Sclerosis (EUREMS), launched in 2011 and run by a consortium of academic institutions and NGOs, aims to address the lack of data at EU and national level on treatment and care for people with MS. While EUREMS has already made important progress in providing a cross-border infrastructure for data collection, analysis,

“What has been most difficult for me is that at times I do not feel that I am worth very much, especially in comparison to the life I led before I ended up in a wheelchair. . . Not so many years ago I was a thriving, up and coming company executive with a great future ahead of me, or so I thought, and was an able sportsman. Now my body deteriorated slowly but surely and I felt I was no longer as clear thinking as previously. Sometimes my short-term memory was impaired. I felt my MS was actively attacking my body physically and mentally.”

[J. Golding, person with progressive MS, Norway]

interpretation and dissemination of results in the MS field, there is still work to do. This project is building a network of over ten national MS registers but many more are needed to gather data from right across the EU.

- The MS Barometer is a tool by which MS societies and their Medical Advisory Boards can report on the current situation for people with MS within their national contexts. This annual survey measures specific aspects of how EU countries manage MS and how policy decisions affect the pressure experienced by people with MS. Yearly results help to identify urgent issues at national level and facilitate comparison across all EMSP member countries. Even greater participation is needed to ensure fully comprehensive results.

- Results from the MS Barometer need to be supported by a Pan-European MS Patient Experience Survey, which EMSP is undertaking. Promotion and regular application of such a survey will be needed to capture up-to-date information on the experiences of people affected by MS across the EU, helping to monitor the situation in different countries in a consistent fashion, identify areas of unmet needs, and assess progress in MS treatment and care.

- In order to be able share research and clinical data to promote swifter learning about MS, standardised MRI and other imaging protocols are needed so data is comparable and more meaningful across studies and populations.

### CALL 7

By 2022, the EU and other research funders must allocate particular attention and resources to research into progressive MS. Researchers must invest increased time and effort into identifying and developing accurate, reliable and economically viable biomarkers for distinguishing relapsing and progressive MS and assessing prognosis. Once validated, such biomarkers should be commissioned and supported across the EU. Further research into understanding and finding treatments for progressive MS is also urgently required.

### CALL 8

By 2024, researchers, research funders and MS organisations across Europe must collaboratively develop a series of shared research and data management strategies, underpinned by central EU resources as well as national level funding. The collection, collation and sharing of relevant MS data must be promoted and encouraged to ensure a comprehensive understanding of MS across the EU and to better inform research projects to drive improvements for people with MS.

## Enabling Employment, Job Retention and Education

“My work has a huge impact on me physically but mentally I need it because it gives me life and I can forget about MS.”

[M. Bartley, person with MS, Ireland]

The extent to which people with MS are disabled by their condition varies greatly and, correspondingly, the extent to which individuals may wish and be able to work also varies. However, many employers are not experienced in managing fluctuating and unpredictable changes in the functioning of employees with MS. Simple workplace adjustments, such as flexibility of working hours or technical aids, could prevent individuals from leaving work prematurely. A supportive work environment, including flexibility in the workplace and awareness amongst colleagues, is a crucial factor in the employment decisions of many people with MS, enabling them to remain at work.

As MS often strikes between the ages of 20 and 40, the challenge of coping with the disease can be exacerbated by the fact that individuals are frequently forced to stop working or retire early due to a lack of support and provisions for their MS-related needs in the workplace. This can put

a strain on households as well as the economy as skills and experience are lost from the workforce. Exclusion from employment has significant negative impacts on the morale and mental wellbeing of people with MS and on economies more broadly. Supporting people with MS in job retention and return to employment has important individual and societal implications. Paid work opens up opportunities, provides income, a sense of purpose, dignity and social connectivity.

People with long-term conditions, such as MS, can also face considerable difficulties in accessing and taking part in education. For example, they may miss time and courses because of their disease, medical appointments or treatment and need adaptations to exam timetables for the same reasons. There can be considerable lack of understanding from education staff and rigid administrative rules failing to account for the needs of these people.

The EU Directive 2000/78/EC on Equal Treatment in Employment and Education stipulates that employers should take steps to accommodate the needs of people with disabilities at the workplace. However, people with MS across the EU report that many employers are not putting in place reasonable measures and people's experiences vary widely between countries. Adapted systems and protective legislation are not always in place and, where they exist, they are usually under-used, with employers and the general population often not knowing about them. While there is the challenge of high unemployment within a difficult economic climate in many parts of Europe, it can be expensive to let people with MS fall out of the labour market and onto social benefits where this can be avoided. It is important that employers are aware of the financial benefits of employing and retaining people with good skills and experience.

There are examples of projects aiming to help tackle these issues:

- EMSP has launched a project to try to address some of the employment difficulties faced by young people with MS in the EU. The Believe and Achieve project aims to create work opportunities for young people with MS through partnerships with businesses across Europe. EMSP and its project partners will enable young adults with MS to access paid traineeships in important corporations.
- The European Network for Workplace Health Promotion is running a campaign aiming to promote healthy, suitable work for people with chronic illnesses and disabilities – either by helping them stay in a job or by supporting their return to work. As well as raising awareness amongst the public, employers and policy-makers, the campaign provides a guide to good practice and example models of good practice.

In addition, the needs of some people with MS can mean that their carers are also forced out of work if workplaces cannot accommodate their needs (see Action Area 5 below). Policies for carers are needed to help address this. For those combining work and care, flexible working arrangements could mitigate reductions in working hours for carers, and should be promoted. For those who opt to temporarily leave the workforce for caring purposes, training and employment support programmes might facilitate their transition back into the workforce.

### CALL 9

By 2018, all employers and education providers must be aware of legislation and policies requiring the need to provide support for people with chronic conditions, such as MS, and take steps to ensure this provision for all those who need it. This may include flexible working arrangements, an adapted work environment or accommodating changes in job roles. Policy-makers, business leaders and unions must be proactive in raising awareness amongst employers and education providers and support them to adapt their business practices accordingly.

### CALL 10

By 2022, all policy-makers and employers must recognise the need for greater flexibility within social, disability and workplace benefits to account for the fluctuating needs of people with relapsing remitting MS. Specific provisions to allow for flux must be put in place to support people with MS, and those with other fluctuating conditions, during the times they are unable to work without penalising them for times when they can work.

## Supporting and Empowering Carers

“He needs round the clock care, permanent, non-stop. He can't manage by himself. Not even to turn himself in bed or to stretch his legs.”

[A. Kleshchanka, wife and carer of person with MS, Belarus]

People with MS often need help performing daily tasks because of health problems and functional and cognitive impairments. This care is mostly provided by informal carers, particularly by spouses and other relatives. It is estimated that more than one million people are affected through their role as carers and family members of people with MS.

Whilst ensuring that the person with MS remains central, it is also vital that carers are adequately supported in their role. The stress and physical burden of caring for MS patients may have an adverse effect on the psychological and physical wellbeing of carers, placing extra demand on health services. In addition, although caregiving can be beneficial for carers in terms of their self-esteem, it can affect their careers as it can be difficult for working-age carers to balance paid work with caring duties, potentially leading to drop-out from the labour market. As MS is often

diagnosed when a person is of working age, the responsibility for their carers often comes at a time when they may have small children and they are not as financially secure or developed in their careers.

The Organisation for Economic Co-operation and Development advises that countries that wish to maintain or increase reliance on family carers will need to alleviate the burden on them and reduce the economic costs associated with caring responsibilities. Policies and interventions, ranging from respite care to psychological support and practical help, could alleviate the burden on carers.

The isolation of carers also needs recognition. For some carers, looking after a person with MS can lead to increased social isolation, possibly as they reduce their work hours and social engagements. Many carers would like to be able to talk to others who are in a similar situation to them, be able to share their experiences and have their voice heard as a key stakeholder in decision-making regarding the person with MS they care for. There is currently a lack of opportunities for carers of people with MS across the EU to interact with others like them and yet this is something that could be resolved with little cost.

“ For many years as an MS peer for caregivers I have realized that there are many caregivers and relatives all round the world who feel deep loneliness and with a great need to share their plight, their feelings, and their thoughts with someone.”

[E. Golding, wife and carer of person with MS, Norway]

**CALL 11**

By 2016, all those who work with people with MS and their carers must take the particular needs of carers into account and offer support where appropriate. This may comprise many aspects such as tailored information, access to financial or employment support, counselling or more involvement in decision-making, without disempowering the person with MS. Services should review the support available in their area and address any gaps that may exist to ensure a full complement of options is available to help the carers they meet and work with.

**CALL 12**

By 2016, the MS community should develop and promote a resource (such as an online hub) enabling MS carers from across the EU to communicate with each other, share their experiences and develop a voice to be able to express their particular needs and preferences. This resource could also be used by MS organisations as one way of reaching carers to consult them on particular issues and identify how best to support them.

It is now time to take action. We all have a responsibility to drive improvements and must work in collaboration if we are to address the issues and Calls to Action set out in *Defeating MS Together*. We ask you to support this Code and work with us to improve the lives of over 700,000 people with MS, and their carers, across Europe.

Together we must:  
Commit. Support.  
Advocate. Act.

## About EMSP

The European Multiple Sclerosis Platform (EMSP) represents more than 700,000 people living with MS in Europe. Their needs are the main focus of our advocacy and awareness-raising campaigns. Our flagship projects aim to improve quality of life as well as access to treatment, care and employment. En route to its ultimate vision of a world without Multiple Sclerosis, EMSP works to ensure that people with MS have a real voice in determining their own priorities.

EMSP was founded in 1989 and over the years we have gained the support of 39 national MS member societies from 34 European countries.

Further information about *Defeating MS Together* and the EMSP may be found on the organisation's website:  
[www.emsp.org](http://www.emsp.org)

### **EMSP aisbl**

Rue Auguste Lambiotte 144, 1030 Brussels, Belgium  
 telephone + 32 2 304 50 15 – fax +32 2 305 80 11

### **Maggie Alexander** *Chief Executive*

+32 2 307 36 22 [maggie.alexander@emsp.org](mailto:maggie.alexander@emsp.org)

### **Christoph Thalheim**

*Deputy CEO and Director of External Affairs*

+32 2 305 80 12 [christoph.thalheim@emsp.org](mailto:christoph.thalheim@emsp.org)

### **Ralf Lehmborg** *Finance and Office Manager*

+32 2 304 50 15 [office.manager@emsp.org](mailto:office.manager@emsp.org)

### **Elisabeth Kasilingam** *Programme Manager*

+32 2 304 50 13 [elisabeth.kasilingam@emsp.org](mailto:elisabeth.kasilingam@emsp.org)

### **Andreea Antonovici** *PA and Event Coordinator*

+32 2 699 05 42 [andreea.antonovici@emsp.org](mailto:andreea.antonovici@emsp.org)

### **Claudiu Berbece** *Communications Coordinator*

+32 2 699 05 41 [claudiu.berbece@emsp.org](mailto:claudiu.berbece@emsp.org)

### **Žilvinas Gavėnas** *IT Coordinator*

+32 2 304 50 14 [zilvinas.gavenas@emsp.org](mailto:zilvinas.gavenas@emsp.org)

### **Yves Brand** *External Affairs Coordinator*

+32 498 159 381 [yves.brand@emsp.org](mailto:yves.brand@emsp.org)

### **Emma Rogan** *Believe and Achieve Project Coordinator*

+353 876 965 403 [emma.rogan@emsp.org](mailto:emma.rogan@emsp.org)

## ADVOCACY

- Ensure the voice and influence of people with MS is recognised
- Campaign for equitable access to high quality treatment, services and employment across Europe

## KNOWLEDGE AND EXPERTISE

- Share and promote evidence-based best practice
- Foster effective cooperation between people affected by MS, health professionals, policy decision-makers and researchers

## RESEARCH

- Encourage and support high quality MS research and international MS research collaboration
- Support the collection, pooling and interrogation of essential MS data across Europe

## IMPROVING THE QUALITY OF LIFE OF MORE THAN 700,000 PEOPLE WITH MS ACROSS EUROPE

European MS data collection for research and better outcomes:

**Defeating MS Together**

Comparative survey of the national situation in up to 33 European countries:  
**MS Barometer**

Online education supporting the crucial role of European MS nurses:  
**MS Nurse PRO**

European Code of good practice in MS:  
**Defeating MS Together**

Multi-media campaign to raise awareness of the impact of MS:  
**Under Pressure**

Improving access to employment for young people with MS:  
**Believe and Achieve**

## Additional references used to inform

### *Defeating MS Together:*

#### EMSP sources

- EMSP. The European Code of Good Practice in Multiple Sclerosis. 2005
- EMSP. Pocket Guide to The European Code of Good Practice in Multiple Sclerosis. 2009
- EMSP. Believe and Achieve.  
[www.emsp.org/projects/believe-and-achieve](http://www.emsp.org/projects/believe-and-achieve)
- EMSP. MS Barometer. 2011.  
[www.emsp.org/projects/ms-id/160](http://www.emsp.org/projects/ms-id/160)
- EMSP. MS factsheet. [www.emsp.org/multiple-sclerosis/ms-fact-sheet](http://www.emsp.org/multiple-sclerosis/ms-fact-sheet)
- EMSP. Under Pressure: Living with MS in Europe.  
[www.underpressureproject.eu/web/living-with-ms-in-europe](http://www.underpressureproject.eu/web/living-with-ms-in-europe)
- EUREMS. [www.eurems.eu](http://www.eurems.eu)
- Feedback from a roundtable event held by EMSP with reps from MS societies and organisations from over 20 countries: [www.emsp.org/news/news-from-europe/225](http://www.emsp.org/news/news-from-europe/225)

## Publications

- European Parliament and Council. Directive 2000/78/EC on Equal Treatment in Employment and Education
- European Parliament and Council. Directive 2011/24/EU on Patients' Rights in Cross-border Healthcare
- European Patients Forum. EPF Briefing: Tackling discrimination and promoting equal treatment for patients with chronic diseases. 2014
- Ghezzi A. Therapeutic strategies in childhood multiple sclerosis. *Therapeutic Advances in Neurological Disorders*. 2010; 3(4): 217-228
- Gupta S et al. Self-reported burden among caregivers of patients with multiple sclerosis. *International Journal of MS Care*. 2012; 14:179-187
- Hartung et al. Disparities in nursing of multiple sclerosis patients – Results of a European nurse survey. *European Neurological Review*. 2001; 6(2): 106-9
- Huppke P & Gartner J. A practical guide to pediatric multiple sclerosis. *Neuropediatrics*. 2010; 41: 157-162
- Multiple Sclerosis International Federation. *Atlas of MS 2013: Mapping multiple sclerosis around the world*. 2013
- Multiple Sclerosis International Federation. *Global economic impact of multiple sclerosis*. 2010

- Multiple Sclerosis International Federation. MS in Focus: Employment and MS. 2010; Issue 16
- The Work Foundation. Ready to work? Meeting the employment and career aspirations of people with multiple sclerosis. 2011
- OECD. Chapter 3: The Impact of Caring on Family Carers, in Help Wanted? Providing and Paying for Long-Term Care. 2011. [www.oecd.org/els/health-systems/47884865.pdf](http://www.oecd.org/els/health-systems/47884865.pdf)

### Other sources

- BRAI.NS Meeting in Barcelona, February 2014 – presentations
- European Commission. Cross-Border Care. Website information: [http://ec.europa.eu/health/cross\\_border\\_care](http://ec.europa.eu/health/cross_border_care)
- European Network for Workplace Health Promotion leaflet: Promoting healthy work for employees with chronic illness
- MS Society (UK). Types of MS. Website information: [www.mssociety.org.uk/what-is-ms/types-of-ms](http://www.mssociety.org.uk/what-is-ms/types-of-ms)
- The challenges of neurodegenerative diseases in the workplace: what can be done at EU level? Panel discussion in the European Parliament report, 9th July 2013, Brussels

# Acknowledgements

## *Defeating MS Together*

was compiled by health policy expert,

**Dr Alexis Willett of Punch Consulting**

[www.punchconsulting.co.uk](http://www.punchconsulting.co.uk)

EMSP acknowledges with gratitude the invaluable contribution of the people with MS, carers, health professionals, policy specialists, member societies and Advisory Group members that generously provided their ideas, expert opinion and advice on *Defeating MS Together*.

EMSP would also like to recognise the financial contribution, in the form of unconditional grants, from our corporate supporters that have enabled us to undertake the detailed research, consultation, development and production of *Defeating MS Together*.

This report has been designed with reference to best practice guidelines on visual accessibility. We welcome your feedback on the contents and design and suggestions for ways of making our publications more useful and accessible.

Please email your comments to  
*office.manager@emsp.org*

*graphic design* Studio van Son  
[www.studiovanson.com](http://www.studiovanson.com)

The photographs in this brochure (except page 5) are from the multi-media **Under Pressure** project.  
[www.underpressureproject.eu](http://www.underpressureproject.eu)

This report arises from the work programme EMSP\_FY2013 which has received funding from the European Union in the framework of the Health Programme. Sole responsibility of the information contained herein lies with the author and the Executive Agency is not responsible for any use that may be made of this information.



Co-funded by  
the Health Programme  
of the European Union



EUROPEAN  
MULTIPLE SCLEROSIS  
PLATFORM

*25 years, and  
more to come,  
as the voice of  
people with MS  
in Europe*

EMSP Rue Auguste Lambiotte 144/8  
1030 Brussels | Belgium  
telephone +32 2 304 5015  
secretariat@emsp.org  
www.emsp.org

*second (larger format) print  
September 2014  
First published MAY 2014*